

21st Century Health Statistics Vision Process

Harrisburg Meeting Summary

November 16, 1999

Introduction and Background

This session was the first of several discussions with state and local collectors and users of health data, as part of the process of helping to shape the Nation's health statistics system for the 21st century.

The process is beginning with a dialog on future health and health care trends, information and communications technology, and public policies. By its end, this process will:

identify forces that will shape health information needs and opportunities for the future; and

formulate a vision for the future that will help guide policy and planning for health statistics programs.

The process is a partnership of the National Center for Health Statistics, the National Committee on Vital and Health Statistics, and the HHS Data Council. This discussion was loosely organized around questions posed in the "Meeting Preparation Workbook" that was distributed to participants prior to the meeting. Not all of the questions in the workbook were covered; nor did the discussion neatly flow in order of the questions. Given that, to the extent possible, the summary below of the discussion is organized by the response to each question.

B. Major Current and Emerging Health Issues

- 1. Identify major trends in health status of the U.S. population in this decade (e.g. chronic conditions, disabilities). Are these trends likely to continue into the next decade? If not, how will they change?**

With the aging of the population, and especially with the increase in the 85+ age group, there is a greater need for care by older Americans. People are living longer with chronic and disabling diseases. The baby boomer population will place increased demands on the health care system.

New health concerns are emerging. For example, while mortality from heart disease and cancer are decreasing, there is an increase in infectious disease, multi-drug-resistant strains, cancer incidence, obesity, violence, and substance abuse, including use of tobacco. AIDS is no longer on the "front burner," because new drugs are keeping people alive longer, but with less attention on this disease, we may see a rise in numbers affected.

Motor vehicle injuries and deaths are rising in Pennsylvania; possible associations include increased driving, cell phones, dangers at construction sites.

Mental health issues are of rising concern. The increase in social fragmentation and isolation is creating a strain in communities and in social support networks. Greater

identification of mental illnesses is leading to rising costs, especially among the elderly. Deinstitutionalization of the mentally ill was also cited as a factor.

With the growing diversity of the population, there is a need to look more closely at *disparities in health and health care*. There is greater racial and ethnic diversity, an increasing uninsured population, and an increasing immigrant population with very different health care needs. Mainstream health providers may not know how to treat certain diseases presented by immigrants, or how to nurse illnesses they are not used to seeing. Some health problems that are thought of as related to income or race may actually be rural health issues.

There is an increased awareness of *environmental links to health*, and we do not have good measures in this area. There is a great deal of misinformation about environmental health issues. The lay public doesn't understand exposure; the mere presence of a plant down the street constitutes exposure, according to them. They see an increase in asthma among children coupled with an increase in bad ozone days, for example, and make conclusions without considering other factors.

In general, there is *widespread skepticism about government institutions*—as well as health care institutions—and this plays out in issues of confidentiality.

Discussants pointed to the need to *define health status* broadly—we cannot study health without looking at factors such as education and income, which affect health status and access to care. There is a greater focus on quality of life, and on health behaviors and conditions related to lifestyle. But while there is greater awareness of an individual's responsibility for their health, some populations will be “left behind” and they will suffer disproportionately.

2. Identify major trends in use of health services and delivery of health care in recent years? (e.g. managed care; physician group practices; migration of encounters to outpatient settings). Are these trends likely to continue into the next decade? If not, how will they change?

Provision of Health Care

This area is becoming increasingly diverse. For example:

More care is being provided in *outpatient settings* and there are fewer hospitalizations.

There is a move from institutional to home and community based *long-term care*, and an increased emphasis on assisted living.

Different communities have different provisions for the *care of the elderly*. Lancaster County, for example, has many services for elderly and more older people are moving there as a result.

We are also seeing consolidation in *health delivery*.

There is an increase in the number of “*for profit*” hospitals.

Health Insurance Coverage

Employers are purchasing less health care for their employees, pricing some people out of plans altogether and increasing the ranks of the uninsured. This is creating a greater strain on public health departments, public hospitals and on other publicly funded safety nets.

Some said that individuals now have *more choices* on fee-for-service vs. managed care, compared to times past when employers chose a plan for everyone; others said that employers are now providing fewer choices.

There is a growing amount of *uncompensated care*. And some of the use of free public health services may be from “refugees” from managed care, who would rather use these services than go through the “intricacies” of managed care.

Changes in Health Care Delivery System

The health care delivery system is complex and fragmented. We know that the system will change, but we really don't know how. Several questions were posed, such as:

Will the trend toward *capitation* as a payment mechanism continue, or will we return to fee-for-service?

Will primary care physicians serve more as *gatekeepers* into the health care system?

Will the *public health system* move more into managed care?

Cost Concerns

Cost effectiveness, competition, and regulation versus cooperation: Increasing regulation of the health care industry has led to tens of millions of dollars being spent by private industry to comply with HIPAA administrative simplification regulations. Other spoke of the positive effects that will result from HIPAA data standardization.

The question was raised as to how money from the tobacco settlement will be used.

There was discussion about the rising costs of *prescription drugs*, especially among the elderly, and whether employers will be able to afford to include pharmaceuticals in their health plans.

New Trends in Health Care

A trend toward *privatization of government functions* in the delivery of care was noted, such as in STD screening and other clinical activities.

Unregulated sources of *alternative care*, such as herbal medicine, are becoming increasingly popular. The increase is seen among the educated and wealthy, as well as

from less-educated, poorer immigrant populations.

We are seeing a growing number of *grass roots coalitions and health alliances*.

Shortages in certain fields in the health care workforce, such as nursing, may drive up costs.

Technology

Technology is changing the way health information and health care are provided. There is an increase in “telemedicine”, and the internet is increasingly being used as a source of health information.

New technology may result in a wider gap between the “haves and have nots”.

With the Internet also comes a proliferation of misinformation and the question of how to filter out good information from bad.

New Advances in Science

Pharmacological advances are creating consumer demand for newer and better drugs.

The provision of *mail order drugs* results in lost opportunities for education in pharmacies.

Advances in genetics are providing more information about genetic risks. Will individuals want to learn about their genetic risks—particularly when they may not be able to do anything about what they find out?

Health Care Disparities

Socioeconomic disparities in delivery of health care are a concern. Another concern is how to improve the quality of care, without knowing how that is defined. The question was raised, for example, as to what constitutes good prenatal care. It was noted that while blacks are getting more prenatal care now, there is an increase in poor health outcomes in pregnancies among blacks.

- 3. Identify anticipated developments in demographics and social policy in next decade, and how they will affect the health system (e.g. aging and diversity of the population; welfare reform).**

This was discussed in the context of other questions. Responses are reported throughout this summary.

C. Health Information Needs Associated with Trends

- 1. What will be the information needs for addressing the issues that you identified above? On the national level? State? Local? (Consider both public and private**

sector needs)

Data Needs- General

Sample size needs to be increased, to be able to study inter-group differences; synthetic estimates are not acceptable substitutes.

It is critical to have accurate data on *race and ethnicity*, but with changing definitions, how will we get denominators and produce trends?

Also needed is “BRFSS-type” *risk-factor data*; quality of life measures; and data on functional status.

The following are needed for better data:

Standards for *quality of life indicators*, as there is currently a lack of agreement. It was suggested that there be a set of nationwide core measures that could then be customized at the community level.

More information about *episodes of care*—beyond that provided in hospitals and physician offices.

Standards to define what is meant by an *encounter* within the health system.

Measurement by levels of *severity of disease*; we need to know not only if someone has diabetes, for example, but what kind—especially in terms of functional status.

More *environmental health* information.

More information about the *uninsured* and why are they uninsured.

Data to *assess needs for certain health professions*; for example, better mental health data is needed to determine need for psychologists and other mental health providers.

Data Needs-State/Local

Discussants said that the single most frequent question they’re asked and can’t answer is *prevalence*—how many people have a particular condition. We know if people have an encounter with the health care system, but not prevalence. Population-based information is needed on prevalence, especially of chronic and disabling conditions, on the local level.

People want to know more about their *community*, and health officials need to provide local area data if we want to have credibility; the lack of data hinders accountability and presents obstacles to partnerships.

A major issue in obtaining data is that of how to reconcile the need for local area data with the concern for *confidentiality*. Discussants said that confidentiality concerns are

stronger in Pennsylvania than in many other areas, and thus there are bigger roadblocks there than elsewhere. Some spoke of the need for a uniform identifier.

Needs for Improving Access to Data

Too much information is still being reported by paper—we need to *report electronically*. Consumers of information do not want to have to go through a “middleman” to get data. But to be able to go directly to the Internet for data, we must solve issues of data-sharing and confidentiality and data standards.

We need to *remove “jargon,”* to make it easier for providers to report information and for consumers to understand what information is being reported.

Technical assistance is needed to help interpret information; different kinds of products are needed for different levels of data users.

The *public must be educated* about sources of information.

2. How can the health statistics system of the next decade and beyond respond to those information needs?

This was discussed in the context of other questions. Responses are reported through the summary.

3. Identify key technological considerations for the health statistics system and for health information more generally, in the next several years (e.g. the internet; health informatics).

Technology permits greater sharing of medical information, but not everyone has *equal access to technology* or the skills to use it.

Further, the use of technology raises major concerns about *confidentiality*. The challenge is to find ways of providing information access to appropriate users, while safeguarding against unauthorized access.

Some discussants said we have to require providers to *collect and share information electronically*.

Others said that we must *get “buy-in”* from providers, as well as from consumers, who first must be willing to allow data about themselves to be exchanged electronically. To do this, we need to be able to show them that the information they provide will be used properly and for beneficial purposes, such as looking at aggregate health.

There was discussion as to whether *more experience with the use of technology* will lead to greater willingness to employ it, or to more concern about potential for abuse and for misinformation.

4. Given your response to all of the above, what would you consider to be the

highest priority needs to be addressed in building the health statistics system of the future?

More cooperation is needed among public and private data collectors and data owners to collect and share information. This requires:

Agreement on *consistent and uniform standards* for data elements, collection methods, and hardware and software for collection and dissemination;

Protecting *confidentiality* and preventing misuse; and

Monetary and technical assistance, and training for state and local health departments and other local entities to fund, track and monitor health data. There is a need to build hyperlinks and other tools to more easily access available information.

D. Roles and Responsibilities for Providing Information and Statistics

1. Identify the most important roles for the public sector in meeting needs for health information and statistics.

The role of the public sector is to:

provide *quality data* and promote improved data quality;

set standards for data and for methodologies of collection;

ensure *confidentiality* of data;

provide *analysis and interpretation* of data;

educate the public, including education about caveats and qualifiers;

ensure more *rapid data release*, and more dissemination through a variety of methods including the Internet;

continue to *monitor disease trends* and disease registries; and

think more “globally” about *data sharing* and multiple uses of data.

Specifically, it was suggested that NCHS should:

establish and help fund state and local user groups to *facilitate use of data* and sharing of information; this should not be limited only to use of NCHS data. User groups could share information about specific topics such as tabulating race, comparability issues, etc.;

support local pilot initiatives and *develop prototype surveys* that states can use on the local level; and

support infrastructure development for state centers, that expands their role beyond that of only vital statistics.

2. Identify the most important roles for the private sector in meeting needs for health information and statistics.

The private sector should:

have the responsibility of *regulatory compliance* with HIPAA and other regulations.

build information systems to provide information over the internet to help their doctors, hospitals and consumers to be better informed decision-makers.

define quality of life, what data is meaningful for outcome measurement, and how to prioritize information needs.

have a role in *improving data quality*, in providing data about *health care delivery system* encounters, and in helping with *interpretation of data*.

3. Identify the most constructive steps that could be taken by the Federal government in meeting needs for health information and statistics.

This was discussed and responses are reported above.

4. Identify the most constructive steps that could be taken by state and local governments in meeting needs for health information and statistics.

State and local governments must:

establish *priorities* and stick to them;

determine what is the *state role* and what is the local role;

get the *data out faster*;

produce *local area* data;

study *health outcomes*;

work with *other states* to solve common statistical and technical issues;

work with *Federal partners* on pilot projects; and

conduct *State Health Improvement Plan (SHIP) data initiatives*.

5. Who are some of the key users of health statistics information and how might we go about gaining their input into the above questions? Please identify any specific individuals or organizations that should be involved in this process.

Several groups were identified, including:

community Action Programs (CAP), community-based indicators projects, and other community-based organizations;

hospitals and state hospital organizations;

cost containment councils;

universities and research departments;

policy makers, including legislators and Governors' offices;

media;

management consultants;

data vendors;

trade associations;

libraries;

the United Way;

various advocacy groups (using Healthy People 2010 to help identify them);

national companies such as HBOC and MEDSTAT; and

purchasers of care, such as benefits managers of business and labor groups.

In general, it was said to be important to contact consumers and well as representatives of government.

Participant List

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